

# **A I D S TREATMENT N E W S**

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# AIDS Treatment News

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## Statement of Purpose:

*AIDS Treatment News* reports on experimental and standard treatments, especially those available now. We interview physicians, scientists, other health professionals, and persons with AIDS or HIV; we also collect information from meetings and conferences, medical journals, and computer databases. Long-term survivors have usually tried many different treatments, and found combinations that work for them. *AIDS Treatment News* does not recommend particular therapies, but seeks to increase the options available.

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The August 2006 Toronto conference of about 25,000 people had no major controversies -- but serious concerns about problems and inadequacies in the response to the global epidemic.

## AIDS Information Overload: What You Can Do Now

by John S. James

### The Problem

The recent International Conference on AIDS in Toronto released 9979 abstracts of research and other AIDS presentations one day before the conference began. If you spent an average of 20 seconds each to look at them, that review would take 55 hours. Clearly the more than 20,000 people who registered for the conference did not have time to look for sessions important to them but not in the obvious places. And most of the research reports created at considerable expense will never get public attention regardless of their merits, and may never reach people who need to know about them.

The problem of too much information to handle well applies not only in conferences but every day in AIDS, as so much is happening that no one could

be aware of it all. A search for HIV on the U.S. medical database at <http://www.pubmed.gov> finds over 200,000 medical publications, largely journal articles. Google finds over 100,000,000 Web pages.

Here is something we can do about information overload.

### **Ideal Wish List**

What could help connect projects and people who should know about each other, so that all AIDS work could be more productive?

We believe the key is personal recommendations by leading experts (including not only physicians and scientists, but also activists, organizers, service providers, or anybody that people want to listen to), pointing out the most interesting information, events, and ideas as they see them, right now. Many experts or teams with different specialties, interests, and perspectives could each recommend online articles, abstracts, reviews, organizations, events, or any other public Web pages of special importance for their audience. Then anyone could choose their own experts to point them to the best information -- or use the choices of any person or organization they trust.

Instead of giving up on following dozens of new articles every week, we could keep up by glancing at the handful selected as most important by experts we picked, for the topics we chose -- and find them all in one place, probably within a day or two of publication.

Experts are busy. But they could just click to recommend a journal abstract or other public document they were looking at anyway -- immediately updating their referral list for the

world. They or others could optionally comment on a recommended item, immediately or any time later. There would be no pressure to look through any particular list of new articles or other Web pages (unless an expert or team agreed, for example, to scan the titles and abstracts of all new articles coming out in certain journals, or to moderate a calendar of events).

To avoid pressure to promote the work of friends or colleagues, the experts could remain confidential if they wanted -- or even anonymous, while still building a reputation based on the value of their recommendations so far.

Unlike reviews and other articles, these recommendations will be current to the day and minute that someone looks at them. The expert can write a description, but does not have to. And anyone registered on Connotea can add a comment.

The big obstacle has been getting the software developed. But it turns out that a good system is already available, free and worldwide.

### **Connotea**

Social-bookmarking software called Connotea (<http://www.connotea.org>) already does most of the above wish list well. It is free, and fully Web-based so it works with almost any computer and browser, with no need to install software. Nature Publishing Group (the publisher of *Nature*, *Nature Medicine*, and many other journals) created Connotea as an open-source project, mainly but not only for use by scientists and clinicians.

The site has excellent guidance for new users on how to get started saving their own bookmarks to almost any Web page. But those who only receive

the information distributions we propose will not need these instructions. They will only need to know how to browse the Web.

We believe that Connotea will be important for sharing news, resources, and other information on AIDS research, medicine, services, and activism.

Any number of experts or organizations can each keep a separate public list of recommendations as online bookmarks (each pointing to a Web page), and publish them not only individually, but also together as a Connotea group. Then anyone online can click a single link to use the group, and easily visit any of the Web pages -- with no signup or registration unless a destination Web page requires it (a disincentive to bookmark such a page). The same experts could be assembled into multiple groups; for example, a vaccine organization might be included both prevention and treatment groups.

These experts can easily annotate, change, or withdraw their bookmarks at any time -- and the change made only once will immediately apply to any number groups.

No one can spam these lists -- since only the owner of a user account can save bookmarks there, and only the owner of a group can add or delete user names from the group. Even "tag spam" cannot get in, as long as searches (if any) stay within the group. Also users can receive updates to any Connotea list by RSS, which cannot be spammed.

Almost all science and medical journals make their articles' abstracts free to the public, so a bookmark can point to the abstract (access to the full text varies from free to very expensive). If there is no abstract and mb

the article is only available to subscribers, then the expert who still wants to note that article could write his or her own summary, put it on the Web, and bookmark it instead of the abstract or article.

Connotea bookmarks can point to almost any page available free to the public on the Web -- even many database accesses that search engines often cannot find. And collections of bookmarks reflect human judgment, not just a search on text.

The end users who receive the information do not need to register with Connotea (unless they want to save bookmarks of their own). Instead they visit and use the Connotea groups just like any standard Web pages -- no special setup or instructions required.

### ***AIDS Treatment News Test Groups on Connotea***

*AIDS Treatment News* has created three groups so far; you can use any of them. If you want to add your own recommendations of Web pages to these collections, contact us (see email at the end of this article).

Note: For current information about each group below, click the word 'page' in '*This group has a [page](#) on the Connotea Community Pages*' (or similar wording).

**<http://www.connotea.org/group/aids-icaac>**

Before the 12,000-person ICAAC conference on treatments for infectious diseases (September 27-30, 2006, in San Francisco) we selected 160 presentations most relevant to HIV and put them in a database at the Web address above. Here you can browse the titles and click any one to see the abstract (if any) posted on the official conference site (<http://www.icaac.org>).

You can also view the titles by subject, by clicking one of the 'tags' on the left column on the page; about 30 tags are listed alphabetically starting with 'adherence'.

Note: These abstracts were posted before the conference. We expect to replace these bookmarks with more recent information.

### **<http://www.connotea.org/group/aids-2006>**

The International AIDS Conference (August 2006 in Toronto) had already occurred when we started the group. We entered a list of Web sites with conference coverage, and will add more as additional sites get theirs online. Let us know if you find omissions.

### **<http://www.connotea.org/group/aids>**

This master group named AIDS (capitalization does not matter) automatically contains everything in the two groups above, and other AIDS bookmarks as well. We are looking for people or organizations to create their own AIDS bookmark lists, so that we can include them in our group.

Note: *AIDS Treatment News* reluctantly reserved the group name 'AIDS' in the Connotea system (by using it). If we had not, then anyone with online access could have done so. We will gladly turn over the name to others, when the community agrees who should manage it. (We also are using the group name 'AIDSNEWS' -- which has exactly the same content as 'AIDS', but will stay with us when 'AIDS' goes elsewhere.)

### **Other Uses**

The AIDS-ICAAC group shows one

way to use Connotea. Here are some others:

- So far Connotea has over 2700 public bookmarks mentioning HIV (over 180 of them saved by this writer). Most of the 2700 are on fundamental research, because most of the users so far have been scientists. You can browse or search these bookmarks on HIV (or other science or medicine topic you want to research) by going to <http://www.connotea.org> and typing 'HIV' in the search bar at the top of the page (for a more focused search, change the search bar from 'All' to 'Find exact tag'). Once you find a bookmark that interests you, you can see all the bookmarks that person saved, and visit those Web pages for leads.

Quotation marks are not required, and capitalization does not matter -- but if a search does not seem to do anything, try clicking the button again.

- Groups of any size located throughout the world can publish recommended articles, action alerts, events lists, etc, like the three example groups above. Each member of the group will have his or her own account and password, but they can publish together so end users just need to click one link (without needing any password).

Note: event organizers or others posting announcements must put them on the Web, not just in email, to be listed. Anyone can do this with a free blog, even if the organization has no Web site.

- A private team could share their Web bookmarks for a project.

- Individuals could keep their own bookmarks, better organized than with a browser.

## **Importance**

Major opportunities are lost because people do not get right to the information they need, and spend much of their time going through material not useful to them. Research slows, new treatments are delayed or not developed, and personal and organizational effectiveness are reduced. People do not see the full cost because they never know what could have been.

It will be easy and almost cost-free to brief anyone interested whenever particularly important information becomes available in an area they selected (for example, the AIDS drug pipeline -- or a crucial action alert on prevention, or on global health). Then anyone could read a few pages each week of abstracts or other summaries, all in one place, to see key developments within a day or two of first publication (sometimes the best time to act if needed). Experts may volunteer because clicking on what they are reading anyway is so easy -- and gives them influence over what is recognized as important.

If you are interested in helping with this project you could contact this writer at *AIDS Treatment News*, [aidsnews@aidsnews.org](mailto:aidsnews@aidsnews.org). Optional: include 'Connotea' in the message title, to be sure to bypass spam control.

## **Integrase Inhibitor MK-0518: Merck Opens Expanded-Access Program**

By John S. James

On September 11 Merck announced that its worldwide expanded-access program for MK-0518 is now open in the U.S. This program is for "patients who are resistant to at least one drug

in all three classes of oral anti-HIV medication, are failing their current regimens, and require a medication to which they may not be resistant."

Patients are ineligible if they are or were in a previous MK-0518 trial, are under 16, are pregnant or breast feeding, have acute hepatitis, or are taking certain medications including phenobarbital, phenytoin, or rifampin. There are other exclusion conditions. This program is for patients unable to participate in the clinical trials.

Because this drug is in the new class of integrase inhibitors, it has an entirely different mechanism of action than previous antiretrovirals. Therefore patients resistant to current medications should not be resistant to it.

For more information on the expanded access program, called Earmrk, visit <http://www.earmrk.com>.

## **Comment**

This is a very important potential drug, but it must be used in combination with other active antiretrovirals. It is usually a mistake to try a new antiretroviral when no others are working, because of the risk of developing resistance to the new drug as well; if possible, patients should wait until more new drugs are available for use in combination. Merck recommends "that patients failing their current regimen receive at least 2 new antiretroviral medications to which their virus is still sensitive" -- including approved drugs still active against that patient's virus.

Fortunately Merck is allowing patients to combine MK-0518 with other experimental antiretrovirals in different companies' expanded access programs, after review and approval.

## **Long-Term Non-Progressors -- International Study Recruiting**

A small fraction of people control HIV well, without needing antiretrovirals. If scientists knew how this worked, they might be able to develop entirely new treatments to enable others to do the same -- possibly a major advance for individual treatment, and also for ending the epidemic.

The Elite HIV Controller Study is collecting a single blood sample from long-term non-progressors anywhere. They will analyze the blood to look for genetic or other differences that might help explain how these people stay healthy.

To be eligible, you must be from ages 18 to 75, have a viral load below 2000 without taking HIV medications, and give informed consent. Although the project is based at Harvard and Massachusetts General Hospital, the blood can be drawn locally so there is no need to travel to the study site.

For more information, see the study's Web page,  
[http://www.mgh.harvard.edu/aids/hiv\\_elite\\_controllers.asp](http://www.mgh.harvard.edu/aids/hiv_elite_controllers.asp).

## **ICAAC Conference In San Francisco, September 27-30**

by John S. James

The 46th annual Interscience Conference on Antimicrobial Agents and Chemotherapy will bring about 12,000 people to San Francisco, September 27-30, 2006. ICAAC focuses mainly on antibiotics, but has significant AIDS presentations this year. The official site is <http://www.icaac.org>.

*AIDS Treatment News* prepared a database of AIDS-related ICAAC presentations, at <http://www.connotea.org/group/aids-icaac>. You do not need to sign up or register in any way. Let us know what other information should be included.

## **Retroviruses Conference: Important Deadlines Soon**

The 14th Conference on Retroviruses and Opportunistic Infections, one of the most important scientific meetings on AIDS, will take place February 25-28, 2007, in Los Angeles. Not everyone can get into this meeting; for more information see <http://www.retroconference.org>

Online abstract submission opened September 11; the deadline for abstracts (except late breakers) is October 3 (5:30 p.m. EDT). This year, researchers can edit their abstracts online until then.

**October 12** is the deadline for Community Educator Program applications, and also for International Scholarship applications.

General registration opens November 28. Registration and housing close January 25, 2007 -- or earlier, if the limit of 3,800 registrations is reached. Early registration is advised.

The Community Press deadline is December 8. The "consumer press" (mainstream press) deadline is January 19.

Late Breaker online abstract submission is December 15 - January 12 (5:30 p.m. EST).

The Pocket Program will be distributed online on February 9.

For other dates and deadlines see the official list at <http://www.retroconference.org>.

## **Genetic Testing May**

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# Avoid Abacavir Hypersensitivity Reaction

by John S. James

A study in Australia showed that a genetic test was very effective in predicting which patient would react badly to abacavir (Ziagen) [1,2]. None of 148 patients who tested negative for HLA-B\*5701 developed the hypersensitivity reaction; three patients who tested positive took the drug anyway, and all of them did have the reaction. The specialized research test used is expensive and has a long turnaround time, but better testing is being developed [3]. The manufacturer of abacavir, GlaxoSmithKline, is conducting a large trial to establish the role of hypersensitivity testing in HIV medical care [4].

The hypersensitivity reaction occurs in about 5% of patients starting abacavir overall, with people of African descent reporting it less frequently. This may be due to the different frequency of the gene in various populations. If the reaction occurs it can be managed with good medical care, but it can be life-threatening if not handled properly.

For a less technical description of the recently published study, see [5].

Also, a Canadian and U.S. group is presenting a similar study [6] as a late breaker at ICAAC (September 27-30, 2006, in San Francisco), Saturday at 8:30 a.m.

## Clinical Study Recruiting Now

An observational study (it does not give any drugs) is recruiting 40 White and 40 African American patients 18 and older who have had a suspected hypersensitivity reaction to abacavir. They will be compared to 200 of each race who have taken abacavir for at least

12 weeks without hypersensitivity. Most needed are African Americans who have had a suspected reaction, since persons of African descent have it less often. In the U.S. there are study centers in more than half of the states, and a list with phone numbers is posted at <http://clinicaltrials.gov/show/NCT00373945>.

## Comment

The Australian experience is an early example of a strategy that will become much more important in the future -- genetic testing to help doctors predict which patients will do well or poorly on a particular drug. Such information will significantly improve both medical treatment with existing drugs, and medical research to find new ones.

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